DOCUMENT RESUME

ED 412 691 EC 305 905

AUTHOR	Mangan, Troy W.; Lakin, K. Charlie
TITLE	Summary of National and State Databases on Residential Services for Persons with Developmental Disabilities. Report 44.
INSTITUTION	Minnesota Univ., Minneapolis. Research and Training Center on Residential Services and Community Living.
SPONS AGENCY	Centers for Disease Control (DHHS/PHS), Atlanta, GA.; Administration on Developmental Disabilities (DHHS), Washington, DC.
PUB DATE	1994-12-00
NOTE	86p.
AVAILABLE FROM	Publications Office, Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Dr., S.E., Minneapolis, MN 55455; telephone: (612)624-4512; $8.
PUB TYPE	Reference Materials - Bibliographies (131) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	*Database Design; *Database Producers; *Databases; *Developmental Disabilities; Elementary Secondary Education; National Surveys; *Residential Institutions; Residential Programs; *Residential Schools; State Surveys

ABSTRACT

This report focuses on the current status of national and state information systems on residential services for persons with developmental disabilities. Ten national databases and 24 state databases are profiled. Each profile presents a summary of the types of information collected and how this information can be accessed. Data elements are presented to identify possible linkages or data aggregations across state data collection efforts or to suggest potential comparisons across states. Each database summary includes the following information: sponsor, population included, purpose/relevance, design, periodicity, geographic level, sociodemographic data, services data, publication of data, and contact person. The report also suggests supports that would assist states in improving, utilizing and sharing their data collection systems. Three tables are provided indicating the individual characteristics, functional characteristics, residential service types, and funding source of the different databases. An appendix lists state database contacts. (CR)

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Summary of National and State Databases on Residential Services for Persons with Developmental Disabilities

Report 44
December 1994

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EC 305 905

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Summary of National and State Databases on Residential Services for Persons with Developmental Disabilities

Report 44

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Preparation of this report was supported by the Centers for Disease Control and the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. The contents of this report do not necessarily reflect an official position of any agency.

ACKNOWLEDGMENTS

The authors wish to thank Mike Vanchiere and Rita Stone, our Project Officers at the Centers for Disease Control and the Administration on Developmental Disabilities, for their support of this project and the National Residential Information Systems Project. We thank Noelle Knapp for preparation of the text used in the report.

We are extremely grateful to our many state respondents who provided the data used in this report. Clearly this report would not be possible without their knowledge and generous assistance. These individuals are listed in Appendix A.

The recommended citation for this report is: Mangan, T.W. & Lakin, K.C. (1994). ***Summary of National and State Databases on Residential Services for Persons with Developmental Disabilities.*** Minneapolis: University of Minnesota, Research and Training Center on Residential Services and Community Living/Institute on Community Integration (UAP).

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CHAPTER 1
INTRODUCTION AND METHODOLOGY

Purpose

As part of maintaining an ongoing state reporting system on residential services for persons with developmental disabilities, staff of the National Residential Information Systems Project (RISP) are well aware that many states maintain program participation and expenditure data that are more comprehensive and detailed than the statistics gathered in the RISP data collection (see "National Data Bases" for a description of the RISP national data base). Indeed, because the purpose of RISP national and state residential data collection is to establish a common set of data elements that can be compared across states or aggregated to yield national statistics, RISP is largely bound by the "lowest common denominator" of statistics that can be reported by states. A number of national and state agencies, including the Centers for Disease Control Division's on Birth Defects and Developmental Disabilities, which partially funded this survey, have expressed interest and requested information on the scope, contents, and accessibility of national and state data bases that include residential services consumers. This *Summary of National and State Data Bases on Residential Services for Persons with Developmental Disabilities* responds to these requests. The effort to summarize available data bases consists of two parts:

- Development of a summary of national data sources yielding information on residential services at the national or census region level, including systems providing state-by-state breakdowns of residential services for persons with developmental disabilities. This list of data sources includes a description of the data source, the relevance of the data source to residential services, and how to gain information or access to the data source. Data sources include national research statistical programs, national administrative data bases (e.g., of the Health Care Financing Administration and the Social Security Administration), and other relevant national sources.

- Development of a summary of comprehensive state data bases containing useful person-level data elements on consumer of state residential services. Data elements in these data bases include measures that can be used to determine the type, size, certification, and other descriptions of use of institutional and residential care provided and individual-level data on the age, gender, race, level of mental retardation, functional abilities and other descriptors of the residential service consumers.

Background

Over the last two decades, the frequency of federal collection of individual-level data on residential and support services for persons with developmental disabilities has been decreasing even as the costs and expenditures have more than doubled in inflation adjusted dollars (Braddock, Hemp, Bachelder, & Fujuira, 1994). This decreasing frequency is due, in part, to reduced real dollar federal support for national disabilities statistical programs, but also to the rapidly growing complexity and associated costs of maintaining national statistics on residential services and service recipients. As an indicator of that growing complexity, between 1977 and 1993 the number of residential settings in which people with developmental disabilities received residential services from government or government-licensed provider agencies grew from 11,000 to over 60,400 (450%), while total service recipients grew only from 247,780 to 308,984 (25%) (Mangan, Blake, Prouty, & Lakin, 1994).

During this same period, as state residential service systems were becoming more decentralized and community-centered, states were giving increased attention to the development of data collection systems for planning, evaluation, and program management purposes. All of this was, of course, supported by rapid growth of computer technology and expertise within state agencies. Ironically, then, as individual-level data collection on persons with developmental disabilities receiving residential services has diminished within federal statistical programs (the last national study being the National Medical Expenditures Survey in 1987 with no projected next national study) there has been a substantial increase in such data collection within the individual states. These state data systems on residential services for persons with developmental disabilities and efforts like RISP to aggregate their data on a national level

are becoming the best available sources of information on residential services in the United States.

This report focuses on the current status of national and state information systems on residential services for persons with developmental disabilities. It presents summaries of the types of information collected and how this information can be accessed. Data elements are presented to identify possible linkages or data aggregations across state data collection efforts or to suggest potential comparisons across states. The report also suggests supports that would assist states in improving, utilizing, and sharing their data collection systems.

Methodology

This study included two parts: 1) identification, review, and summary of current national data bases and 2) a survey of states to identify current data bases, data collection and aggregation procedures, types of data elements, data access, and the types of data summaries and reports generated. The summaries of the national data sets in this report were carried out by RISP staff members; data elements in the states' data sets included in this report were coded in some instances by RISP staff and in others by the state respondents.

Based on an initial review of select federal and state-level data sources (e.g., the National Medical Expenditures Survey, the National Health Provider Inventory, the State of New York Developmental Disabilities Profile), a set of indicators for persons with developmental disabilities receiving residential services in residential settings was developed. This set is comprised of 51 items across four areas: Individual Characteristics, Residential Services, Other Services Received, and Costs. For data collection purposes, the 51 indicators were grouped into six checklists (see Appendix B). A seventh checklist asked for information about data accessibility (i.e., privacy and confidentiality), reports generated from this information, and availability of the data collection/aggregation forms.

Data collection forms were sent to the RISP key respondents from each state in June, 1993. For each form, respondents were asked to record the name of the data set and check off those indicators included in the set. If there were indicators that were not part of a specific data set, respondents were asked to fill the database name blank with "other" and check off the appropriate indicators.

Follow-up telephone calls were made to each respondent to answer questions and solicit feedback. Several respondents suggested alternate persons as respondents. These alternate respondents were then contacted and sent data collection forms. Telephone follow-up calls were made to non-respondents. Completed data collection forms were received by mail or fax. Upon receipt of completed data collection forms, respondents were telephoned to verify their responses. Responses were summarized and profiles were developed of a select group of databases and these profiles were faxed to respondents for review.

While the survey data were provided by informants who were generally well-versed with their states' survey formats and questions, their responses reflect their knowledge of their states' information system. And while respondents were asked to verify the summaries of their responses prepared by RISP staff, no external verifications were conducted.

CHAPTER 2
NATIONAL DATABASES

This review of the currently available national data sets including persons with developmental disabilities receiving residential services are limited to data conducted no earlier than 1985. A total of 10 data sets of interest were identified. These are summarized on the following pages.

National Health Provider Inventory

Sponsor

National Center on Health Statistics

Population Included

A national census survey of nursing homes and personal and board and care homes. Total persons with mental retardation are identified.

Purpose/Relevance

The purpose of the National Health Provider Inventory (NHPI) is to obtain current information from facilities that provide health care, including hospitals, nursing and related care homes; and facilities that provide some kind of personal care, board and care, or domiciliary care. Information is collected about each facility's ownership, number of beds, certification status, and other facility-related characteristics. Information about facility's residents is also collected. Persons with mental retardation are included when they live in nursing homes and board and care homes.

Design

The Bureau of the Census conducts this survey. Two forms are used, one for nursing homes and board and care homes (the survey of interest), and another, similar form for home health care and hospices. All data are aggregated at the facility level.

Frequency

The NHPI was last implemented in 1991. This study was formerly known as the Inventory of Long-Term Care Places (ILTCP) and National Master Facility Inventory (NMFI).

Geographic Level

National; state breakdowns can be carried out.

Sociodemographic Data

- Age (21 or younger, 22 through 64, 65 through 84, 85 or older)
- Gender
- Race/ethnicity
- Primary diagnosis (includes mental retardation)
- Residents in facility the previous night

Services Data

- Services
  - oversight
  - medication administration
  - bathing
  - dressing
  - mobility
  - money management
  - laundry
  - training
  - therapy
  - transportation

- Service hours
  - Physician
  - Registered Nurse
  - Licensed Practical Nurse
  - Nursing Assistant
  - Home Health Aide
  - Dietician
  - Occupational Therapist
  - Certified Occupational Therapy Asst.
  - Speech Pathologist
  - Psychologist
  - Podiatrist
  - Physical Therapist
  - Physical Therapy Assistant
  - Recreation Therapist
  - Social Worker

Facility Data

- Facility/home category
  - Nursing home : if so, what type of nursing home is it? (nursing facility certified by Medicare or Medicaid, ICF-MR certified, nursing home unit of a retirement center, other)
  - Board and Care home (e..g, group home, adult foster care)
  - A home for mentally retarded or developmentally disabled persons
- Number of ICF-MR beds

Publication of Data

Data from the 1991 NHPI is currently available; data on mental retardation facilities in the 1986 ILTCP were summarized in:

Sirrocco, A. (1989). *Characteristics of facilities for the mentally retarded, 1986.* (Vital and Health Statistics, Series 14, No. 4). Hyattsville, MD: National Center for Health Statistics.

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National Nursing Home Survey

Sponsor

National Center on Health Statistics (NCHS)

Population Included

A stratified national sample of persons living in nursing homes. Sample members with primary and secondary diagnoses of mental retardation and other categorical related conditions can be identified.

Purpose/Relevance

Concern about the appropriateness of nursing homes as residential placements for persons with mental retardation has increased substantially over the last two decades. The Omnibus Reconciliation Act of 1987 (P.L. 100-263) placed restrictions on the circumstances under which persons with mental retardation and related conditions can be placed in Medicaid-reimbursed nursing facilities. Persons with mental retardation and related conditions in nursing homes must require the nursing/medical services offered and the facility must meet the individual needs for active treatment.

Design

This survey was administered in 1977 and 1985. Both surveys used a two-stage sampling procedure, which involved controlled sampling within size strata of nursing home included in an updated version of the National Master Facility Inventory (NMFI). In 1977, residents with mental retardation receiving long-term care in nursing homes could be identified by mental retardation being indicated as their primary diagnosis. It was also possible to identify persons with other primary diagnoses who had mental retardation indicated as a secondary disability.

The same guidelines were used in 1985, except that the International Classification of Diseases (ICD) code was used to indicate primary and secondary diagnoses. Persons with mental retardation and related conditions are included in the National Nursing Home Survey if they are among the random sample of residents. The total yield of sample members with mental retardation as a primary diagnosis is only about 150 individuals.

Periodicity

The NNHS was conducted in 1977 and 1985. The next fielding of the survey was scheduled to occur in 1995. However, because the National Medical Expenditure Survey, which also includes nursing homes as well as mental retardation/developmental disabilities facilities, is heavily funded and is scheduled for fielding in 1996, the next fielding of the National Nursing Home Survey is unclear.

Geographic Level

National, no state breakdowns can be carried out.

Sociodemographic Data

- Age
- Primary diagnosis
- Gender
- Marital status
- Prior residence
- Additional conditions
- Senility
- Mental Illness

- Hardening of the arteries
- Heart trouble
- Limitations
- Mobility
- Vision
- Hearing
- Requires assistance with: bathing, dressing, eating, toileting
- Prior residence

Services Data

- Therapy Services
- Physical Therapy
- Occupational Therapy
- Recreation Therapy
- Speech and Hearing
- Psychological or psychiatric evaluation and/or treatment
- Payment
- Facility certification

Publication of Data

The most comprehensive summary of data on nursing home residents with mental retardation is:

Lakin, K.C., Hill, B.K., & Anderson, D.J. (1988). *Persons with mental retardation in nursing homes in 1977 and 1985: A comparison of findings from the 1977 and 1985 National Nursing Home Surveys* (Brief No. 31). Minneapolis: University of Minnesota, Center for Residential Services and Community Living.

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National Medical Expenditure Survey

Sponsor

U.S. Agency for Health Care Policy and Research

Population Included

A stratified national sample of persons with mental retardation/developmental disabilities (MR/DD) in MR/DD facilities.

Purpose/Relevance

The National Medical Expenditure Survey (NMES) was first fielded in 1987. The NMES includes a household survey component and an Institutional Populations Component (IPC). In 1987 the IPC drew relatively large samples of nursing and personal care homes (N=800) and facilities for persons with mental retardation (N=700) and over 3,300 residents the nursing homes and 3,600 from the MR/DD facilities. The IPC contains a great deal of information related to functional and health status and services received by persons receiving long-term care services, including specifically persons in residential services for persons with mental retardation/developmental disabilities. Interest in long-term services derives from the rapidly growing expenditures for care in institutional and related settings under Medicaid and other public and private programs.

Design

The 1986 Inventory of Long-Term Care Places (ILTCP) provided the sample frame for NMES. The Inventory served to identify facilities primarily serving persons with mental retardation, verify eligibility as a "mental retardation facility," and to provide statistics on population and administrative characteristics of facilities on which the sample stratification and eventual weighting could be based. "Mental retardation facilities" were defined as state licensed, contracted or operated living quarters which provided 24-hour, 7-day-a-week responsibility for room, board, and supervision of persons with mental retardation.

The ILTCP, and as a result, the NMES, substantially under-identified the smaller residential settings serving persons with mental retardation. The undercount of places with 1 or 2 residents was so substantial that they were dropped from the NMES sample frame altogether, but the under-count remains evident in the other facilities with 15 or fewer residents. The individual sample included 3,618 people living in MR/DD facilities. However, because of the limitations in the sample frame, sample weightings yielded a national estimate of persons in MR/DD residential settings that was about 40,000 below numbers reported directly by states in the RISP survey for 1987.

Periodicity

The NMES is scheduled to be conducted again in 1996, but will not include MR/DD facilities.

Geographic Level

National; no state breakdowns are possible.

Sociodemographic data

- Age

- Race
- Marital status
- Degree of mental retardation: borderline, mild, moderate, severe, profound
- Related conditions: epilepsy, cerebral palsy, autism, spina bifida, blind, deaf
- Mental disorders
- ADLs
  - bathing/showering
  - dressing
  - toileting
  - getting in and out of bed
  - feeding self
  - walking across a room
- Instrumental ADLs
  - use of telephone
  - managing money
  - shopping for personal items
  - use of personal or public transportation
- Problem Behaviors/Moods
- Medical Conditions
- Use of Special Equipment/Devices
- Sight and/or hearing problems
- Communication problems
- Social and mental functioning
- Employment Status and Wages: works for pay, location of employment, type of employment, work with non-handicapped people, hourly wages
- Resident Movement: if discharged, when, to what type of facility, number of residents at that facility. Where did the resident live before their current residence

Facility data

- Operation (private for profit, private non-profit, public)
- Size, including number of persons with mental retardation
- ICF/MR certification
- Routine services provided
  - nursing or medical care
  - supervision over residents who administer their own medication
  - help with bathing
  - help with dressing
  - help with correspondence or shopping
  - help with walking or getting about
  - help with eating
  - help with communication
- Type of physician services available
- Facility category
  - state institution

- •foster home for persons with mental retardation
- •group residence for persons with mental retardation
- •semi-independent living program for persons with mental retardation
- •some other kind of place for persons with mental retardation
- •family providing services exclusively to relative(s) with mental retardation

- •Types of services provided
  - •physical therapy
  - •occupational therapy
  - •counseling or psychotherapy
  - •speech therapy
  - •hearing therapy
  - •self-care training
  - •independent living skills training
  - •academic/pre-academic training
  - •recreation services
  - •case management services

- •Transportation services
- •Education services

Publication of Data

The most comprehensive summary of statistics from the 1987 NMES is:

Lakin, K.C., Hill, B.K., Chen, T.H., and Stephens, S.A. (1989). *Persons with mental retardation and related conditions in mental retardation facilities: Selected findings from the 1987 National Medical Expenditure Survey* (Report No. 29). Minneapolis: University of Minnesota, Center for Residential and Community Services.

Other reports of interest include:

Cunningham, P.J., & Mueller, C.D. (1991). Individuals with mental retardation in residential facilities: Findings from the 1987 National Medical Expenditure Survey. *American Journal on Mental Retardation, 96*, 109-119.

Altman, B.M., & Cunningham, P.J. (1993). Dynamic process of movement in residential settings. *American Journal on Mental Retardation, 98,* 304-316.

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Public Residential Facilities for Persons with Mental Retardation

Sponsors

Association of Public Developmental Disabilities Administrators in conjunction with the Center for Residential Services and Community Living (University of Minnesota)

Population Included

All public residential institutions (16+ residents) for persons with MR/DD in the United States.

Purpose/Relevance

This database follows the continuing depopulation of state institutions in the United States and contains information on the number and characteristics of persons with mental retardation and related conditions living in state institutions, their movement into and out of those institutions, the costs of state institutions, and state institution closures. This survey has been conducted since 1964 and has been linked to earlier statistical programs of the Bureau of the Census (1922-1946) and the National Institute of Mental Health (1947-1966) and is currently funded as part of the National Residential Information Systems Project at the University of Minnesota.

Design

Basic information is gathered through the use of a 22-item questionnaire.

Periodicity

Biannually. Most recent data collection is June 30, 1994.

Geographic Level

National; state breakdowns can be carried out.

Sociodemographic Data

- Gender
- Age
- Level of mental retardation
- Secondary conditions
- Functional characteristics
- Previous placement
- Placement discharged to

Facility data

- Rated bed capacity
- Total number of residents (all diagnoses)
- Average daily population of residents
- Number of residents at beginning of fiscal year
- New admissions
- Readmissions
- Discharges
- Deaths
- Number of residents at end of fiscal year
- Average per diem
- Staffing
- Community services

Publication of Data

Lakin, C., Prouty, R., Blake, E., Mangan, T., and Bruininks, R.H. (1993). *Residential services for persons with developmental disabilities: Status and trends through 1991.* Policy Research Brief. Minneapolis, MN: University of Minnesota, Research and Training Center on Residential Services and Community Living/Institute on Community Integration (UAP).

Scheerenburger, R.C. (1992). *Public residential facilities for persons with mental retardation, 1990-1991.* Minneapolis: National Association of Superintendents of Public Residential Facilities (distributed by the University of Minnesota Research and Training Center for Residential Services and Community Living/Institute on Community Integration (UAP).

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National Residential Information Systems Project-Annual State Statistics

Sponsors

Administration on Developmental Disabilities
Health Care Financing Administration

Population Included

Persons with mental retardation/developmental disabilities receiving residential services in the United States.

Purpose/Relevance

The National Residential Information Systems Project (RISP) carries out an annual survey of all national and state-by-state statistics on persons with developmental disabilities receiving residential services. Data collection includes breakdowns by various size and type of facility categories. RISP also conducts secondary analyses of other databases relevant to maintain the current and comprehensive statistics in residential services for persons with developmental disabilities and gathers and synthesizes policy relevant data from state agency reports and databases and through special state surveys. The databases used in these secondary analysis are described elsewhere in this summary as in the biannual state institution survey.

Design

State data collection and reporting on residential services is voluntary; all 50 states and the District of Columbia participate.

Periodicity

Annually.

State and Facility Data

The project provides current information on the number of persons receiving services by the size and type of their residential environment, their state/nonstate operation, and their Medicaid participation. The project also gathers data on the costs, resident movement, and other administrative features of state institutions on an annual basis and information on resident characteristics, staffing, budget cost centers, and other detailed resident and administrative data in a biannual survey of each state institution.

Publication of Data

Each year the project disseminates an average of over 2,000 individual reports and data summaries on residential services and responds to over 200 requests for specific data on residential services from state and federal administrative and legislative agencies, advocacy organizations, media, academic audiences, and others.

Mangan, T., Blake, E.M., Prouty, R.W., and Lakin, K.C. (1994). *Residential services for persons with mental retardation and related conditions: Status and trends through 1993.* Minneapolis: University of Minnesota Center on Residential Services and Community Living, Institute on Community Integration/UAP.

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Online Survey, Certification, and Reporting System

Sponsor
Health Care Financing Administration (HCFA)

Population Included
All ICFs-MR in the United States.

Purpose/Relevance
The Online Survey, Certification, and Reporting System (OSCAR) is a HCFA database that contains the outcomes of monitoring ICF-MR facilities. It includes a face sheet that includes resident and administrative data on ICF-MR facilities as well as the outcomes of the individual facilities' survey.

Periodicity
The OSCAR file is updated on an ongoing, facility-by-facility basis subsequent to each facilities' ICF-MR inspection.

Geographic Level
National

Sociodemographic data
- Age
- Gender
- Level of mental retardation
- Other disabilities
- Ambulation
- Speech/Language impairment
- Hearing Impairment
- Visual Impairment
- Drugs to control behavior

Facility Data
- Type of control/ownership
- Staffing
- ICF-MR unit residents
- ICF-MR beds
- Number attending off-campus day programs

Products
Requests for specific reports should be sent to Pete Burdette (see below) and should be as specific as possible in regard to the desired variables and media on which the report is issued (paper, diskette, or tape). There is a basic charge of $50 for a report and cost increases as a function of the media used, the number of facilities included in the report, and other factors. The general turn-around time is four weeks, although this can vary. The RISP is currently summarizing 1993 ICF-MR data from the OSCAR and comparing with 1977 and 1982 ICF-MR states from RISP Census surveys. Reports on this database should be available by the end of 1994.

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National Health Interview Survey: 1994-1995 Disability Supplement

Sponsor

National Center on Health Statistics

Population Included

A stratified sample of non-institutionalized persons with disabilities in the United States.

Purpose/Relevance

The purpose of the National Health Interview Survey's (NHIS) Disability Supplement is to collect data that can provide national estimates of conditions, limitations, needs, and service use of persons with disabilities in the United States. The data can also be used to develop some simple prevalence estimates of certain disability conditions and limitations and provide descriptive baseline statistics relevant to the status and services used by persons with disabilities. The Disability Supplement was designed to consolidate four major national surveys related to disability that had been designed in 1989 and 1990.

Design

Because of the low frequency of occurrence of disabilities within the non-institutionalized civilian population, the sample design for the Disability supplement will be administered over two years (from mid-1993 to mid-1995) and will be enhanced by the over-sampling of people with disabilities.

Disability Supplement 1 is administered to any available household respondent for all related household members and asks about, among other things, the presence of some limitations or specific conditions in household members. Data from this phase will be used to make estimates of key physical or mental limitations and as a screening device to determine eligibility for the other questionnaires. The screening questionnaire asks about (1) pathology and/or impairment, (2) functional limitation, and (3) social disability. These factors are then used to determine eligibility for the second phase of the disability supplement.

Disability Supplement 2 is administered to the individual who meet the definition of "disability" approximately two months after Disability Supplement 1 is completed. Disability Supplement 2 addresses issues such as (1) types and benefits used by the person with a limitation, (2) work or school-related difficulties experienced by the person, (3) needs related to transportation, housing, and other environmental barriers, (4) participation in social activities, (5) experiences with pain or depression that may be associated with health problems, and (6) engagement in health risk behavior activities.

Periodicity

The Disability Supplement will be first implemented between mid-1993 and mid-1995; no plans for future disability supplements exist at the present time.

Geographic Level

National; state estimates are not possible.

Sociodemographic Data

Disability Supplement 1 gathers data about all members of the household and includes questions about Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living

(IADLs) such as eating, getting in and out of bed, dressing, bathing, walking, toileting, taking medicine, and preparing meals. For children, developmental milestones are used.

Disability Supplement 2 gathers data about types of services and benefits used by the person with a limitation, work or school-related activities, needs related to transportation, housing, or other environmental barriers, participation in social activities, experiences with pain or depression that maybe associated with health problems, and engagement in health risk behavior activities. The supplement is person-specific and asks questions about use of equipment and assistive devices, access to needed equipment and devices, and difficulties caused by not having needed equipment or access to particular environments.

Products

Public use tapes for the 1993 survey should be available December, 1994. Public use tapes for the 1994 survey should be available December, 1995.

Contacts

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Division of Health Interview Statistics
National Center for Health Statistics
or
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Public Expenditures for Mental Retardation and Developmental Disabilities in the United States

Sponsor

Administration on Developmental Disabilities

Population Included

The principal mental retardation and developmental disability state agencies in all 50 states and the District of Columbia.

Purpose/Relevance

This database describes the financial and programmatic structure of existing service delivery systems in all states and provides a quantitative assessment of state-federal fiscal commitment to persons with developmental disabilities and their families. The following indicators are used: (1) the amount of federal and state financial expenditures for services to persons in institutional and community service settings and for certain discrete programs (e.g., family support); (2) changes in these expenditures on an annual basis since 1977; and (3) the numbers of individuals receiving services in certain program categories.

Design

The primary focus of the study are the activities of the principal mental retardation and developmental disability state agencies (especially MR/DD and Medicaid agencies). Information about these activities is obtained from copies of the published executive budget documents from each state and D.C. Two broad classification were employed in the analysis of spending trends: (1) large (16+) congregate care services and (2) community services, including places serving 6 or fewer people and 7-15 people.

Periodicity

States are surveyed every four years, but data are gathered retrospectively to complete annual profiles. The last data collection was for Fiscal Year 1992.

Geographic Level

State-by-state and national

Service Delivery Data

Service delivery profiles are developed for each of the 50 states and Washington D.C. Each profiles consists of figures depicting: (1) comparative adjusted MR/DD spending for large congregate care residential care and community services; (2) revenue sources for community services spending; (3) number of individuals served by size and auspices of ownership of residential setting; (4) institutional services data on the average number of daily residents, revenue sources, per diem, and spending by level of government; and (5) MR/DD spending in the state as a percentage of aggregate statewide personal income

Client services data

Client services data includes the number of clients served in residential services (divided into those in settings with 15 or less or 16+ residents), number served in non-residential community services (e.g., sheltered employment, day habilitation services), and number served in/by other

non-residential services (e.g., case management, Home and Community Based Services Waiver, and Model 50/200 Waiver programs).

Expenditures data

This database also contains information on expenditure data and number of individuals served in the areas of family support, supported employment, early intervention, and aging/DD services as well as data on clients and expenditures associated with persons with mental retardation residing in nursing homes.

Products

Braddock, D., Hemp, R., Bachelder, L., and Fujiura, G. (1994). *The state of the states in developmental disabilities: Fourth national study of public spending for mental retardation and developmental disabilities in the United States.* Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

Contacts

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or
Richard Hemp
Illinois UAP on Developmental Disabilities
The University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, IL 60608
(312) 413-1647

Medicaid Statistical Information System (MSIS)

Sponsor

Division of Medicaid Statistics
Office of Statistics and Data Management (OSDM)

Population Included

All Medicaid recipients with MR/DD in the United States.

Purpose/Relevance

Medicaid Statistical Information System (MSIS) contains data on all Medicaid recipients that can be analyzed on a national, state-by-state, and individual basis, including Medicaid recipients with mental retardation, who can be identified by primary and secondary diagnosis codes. The MSIS summary file was designed to provide a single data source to provide analysis of state-supplied Medicaid eligible, recipient, and paid claims data. This summary provides personal level information which includes summations of utilization data. This system does not have a mechanism for identifying persons receiving services under any type of Medicaid waiver.

Design/Periodicity

Summary files are created by using each state's quarterly validated Eligible and Claims files, any prior year fourth quarter summary files, and prior quarter current year summary file. These files are merged together to create a new quarterly, year-to-date, summary file. Each record (for each person who was eligible for Medicaid for one day during the reporting quarter or year) on the summary file has a unique identification number.

Geographic Level

Data is available on a national and state-by-state basis.

Sociodemographic Data

- Age
- Date of death
- Gender
- Race
- Social Security Number
- Primary diagnosis (ICD-9-CM)
- Secondary diagnosis (ICD-9-CM)

Service Utilization Data

- Days of long-term care in an ICF-MR certified facility

Products

Claim level (e.g., client level) data is not typically used by the MSIS system. Requests for reports that involve claim level data must come from the study Project Officer and a HCFA or HHS approved contractor. Costs of processing a report need to be covered by interagency payment. Data and reports are available recorded on magnetic tape, by state and/or nationally, and by quarter and/or Fiscal Year.

Contacts

Administrative Contact:
Richard Beisel, Director (410) 597-3905

Technical Assistance Contacts:
Nelson Berry (410) 597-3894
Julius Hodges (410) 597-3893
Fax: (410) 597-5152

Mailing address:
Health Care Financing Administration
BDMS/OSP/DMS
Medicaid Statistical Information System
2-A-2 Security Office Park Building
6325 Security Boulevard
Baltimore, MD 21207

Annual Report on Home and Community-Based Services Waiver

Sponsor

Medicaid Bureau

Population Included

All persons with MR/DD served through the Medicaid Home and Community-Based Services (HCBS) Waiver.

Purpose/Relevance

This database contains information on numbers of persons with mental retardation and related condition expenditures for their care served through the Medicaid Home and Community-Based Services (HCBS) Waiver.

Design

States are asked to fill out and return the data collection instrument (Form HCFA-372) to the Medicaid Bureau within six months after the end of their waiver year, which varies from state to state. A separate form is required for each type of HCBS waiver. Those states with less than 200 people in the waiver only need to fill out Sections 5-8 (see below for a description). Because some states are late with their data, this database probably provides an underestimate of expenditures and number of people served.

Periodicity

Annually

Geographic Level

State-by-state

Services Data

Level(s) of care in approved waiver: SNF/ICF/ICF-MR
Categories of recipients:
Institutional Long-Term Care (LTC) recipients
ICF/MR services: non-waiver recipients/waiver recipients
ICF/all other services: non-waiver recipients/waiver recipients
SNF services: non-waiver recipients/waiver recipients
Mental health facility SNF/ICF services: non-waiver recipients/waiver recipients
The database contains eight sections:

1. Annual number of institutional long-term care recipients with waiver;
2. Annual expenditures for institutional long-term care with waiver;
3. Annual number of institutional long-term care recipients who receive acute care services;
4. Annual expenditures for acute care services to institutional long-term care recipients;
5. Annual number of Section 1915(c) Waiver recipients;
6. Annual Section 1915(c) Waiver expenditures;
7. Annual number of waiver recipients who receive acute care services;
8. Annual expenditures for acute care services to waiver recipients; and
9. Data not specifically related to formula factor values

Products

There is no regular distribution of reports. Each year a report is developed that describes total Medicaid expenditures for HCBS and total number of people served through HCBS. Some breakdowns across populations (e.g., persons with mental retardation, the elderly) are also provided. Further breakdowns can be done by individual users and/or agencies.

The Center for Residential Services and Community Living at the University of Minnesota is currently collecting HCFA 372 data directly from individual states and assessing the reliability with HCBS recipient and expenditure data obtained from the HCBS program manager in each state.

Contacts

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CHAPTER 3
STATE DATABASES

This review of state databases includes descriptions of the most useful of 94 state databases identified in our survey of states. The databases profiled from states below were selected on the basis of their comprehensiveness in describing consumer characteristics and residential types. In general, the databases are used for individual-level program planning, service planning on a local, regional, and state level, and for tracking services and individuals. See Tables 1-3 (p. 73) for a summary of these databases.

Comprehensive Alabama Mental Health and Mental Retardation Information System (CARES)

State

Alabama

Population/Purpose

CARES is an online, state-wide database that is accessible by each facility and central office. It is used to support the clinical functions performed by the DMH/MR facilities.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism*
  - Cerebral Palsy*
  - Epilepsy*
  - Spina Bifida*
  - Other*
- Sensory
  - Vision*
  - Hearing*
- Medical conditions
  - Medications
- Functional Abilities/Limitations
  - Mobility
  - Eating
  - Other
- Communication
  - Skills: special disabilities
- Problem Behavior
- Psychiatric Diagnosis

*Data fields are available to record this information. Reports are not hard-coded for each sort but could be obtained from the database.

Residential Service Types Included

- Nursing home*
- State institution
- Nonstate group home*
- Foster home*
- Semi-independent living*
- Supported living*
- Family/Relative home*
- Other residential service type*
- Waiting for residential services*

*Data field is available to enter "current location" for each person known to the system.

Residential Services: Funding Sources

- ICF-MR: Data field is available to denote whether a person is eligible for ICF-MR funding.

Other Services Received

- Vocational
- Habilitation
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Transportation
- Psychological/Psychiatric Services
- Other

Data Availability

Data is confidential.

Contact

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Director of Facility Services
Department of Mental Health/Mental Retardation Division
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Montgomery, AL 36109
Phone (205) 271-9295 Fax (205) 270-4692

Client Developmental Evaluation Report (CDER)

State

California

Population/Purpose

The CDER collects information on developmental status (adaptive and problem behavior, diagnostic problems, and demographics for all of California's residential service recipients (Database currently includes 130,350 people). Applicable to all types and levels of developmental disabilities.

Sociodemographic Data

- Diagnostic element
  - Age
  - Gender
  - Height
  - Weight
  - Disability
    - Autism
    - Epilepsy
    - Seizure disorder
    - Other type of developmental disability
  - Risk Factors
  - Mental Disorders
  - Chronic medical conditions
  - Hearing
  - Vision
  - Behavior Modifying drugs
  - Abnormal Involuntary movements
  - Special Health Care Requirements
  - Special conditions or behaviors
  - Special legal conditions
- Evaluation Element
  - Motor Domain
  - Independent Living Domain
  - Social domain
  - Emotional domain
  - Cognitive domain
  - Communication domain

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Foster home
- Supported living
- Family/Relative home
- Other residence

Data Availability

Data collection forms are available.

Contact

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Community Contract and Management System (CCMS)

State

Colorado

Population/Purpose

The Community Contract and Management System (CCMS) is a self-contained computer system designed and programmed by the Division for Developmental Disabilities for operation on remote micro-computers at service agencies. Information is transmitted to the Division monthly to update state-wide files. CCMS includes identifying, demographic, program, and service information for individuals receiving or waiting for services; it is also used to prepare the monthly billings for services provided by agencies operated by or under contract to the Division. It calculates total bills, produces contract status reports, prints Medicaid claim forms, and tracks billing status changes.

Sociodemographic data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Other
- Sensory
  - Vision: "significant impairment"
  - Hearing: "significant impairment"
- Medical conditions
  - "medically fragile"
- Functional Characteristics
  - Mobility: "mobile/non-mobile"
- Communication Skills
  - "significant speech impairment"
- Problem Behavior
  - "maladaptive behavior requiring intervention"
  - "DD/MI dual diagnosis"

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Foster home
- Supported living
- Family/Relative home
- Other residence
- Waiting for residential services

Residential Services: Funding Sources

- ICF-MR
- HCBS
- Community Supported Living Arrangement (CSLA)
- State-only

Other Services Received

- Case Management
- Vocational
- Habilitation
- Transportation: "for HCBS only"
- Other

Expenditures for Services

- Residential/Personal Assistance
  - Expenditure information available for community services and state-run group homes, not ICF's-MR
- Vocational

Data Availability

All individual data may be released without identifying data if a person cannot be identified from that information. Aggregate reports may be released.

Contact

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Colorado Progress Assessment Review (COPAR)

State

Colorado

Population/Purpose

The COPAR was developed by Colorado's Division for Developmental Disabilities (DDD) to evaluate actual outcomes for persons receiving support with respect to the Division's mission statement, which established community inclusion, responsible choice, control, belonging, relationships, competencies, talent, security, and self-respect as the primary values that should be reflected in services to Colorado's citizens with developmental disabilities.

The COPAR asks structured and unstructured questions directly to a sample of persons receiving services, and providers of services on a longitudinal basis to determine program and service outcomes and differences across programs and regions. Questions are also asked pre and post participation in new services initiatives to determine if they have resulted in improvement in the lives of persons served. The COPAR is conducted on a random sample of adults receiving services and findings can be extrapolated to Colorado's full service population.

COPAR is based on review of items from several other forms, including the Consumer Satisfaction Scale (Temple University), Staten Island Activity checklist (Staten Island Developmental Center, New York), Quality of Life Questionnaire (Mid-Nebraska MR Service, Inc.), Consumer Interview and Consumer Opinion Questionnaires (New York Office of Mental Retardation and Developmental Disabilities), Outcome Based Performance Measures (Accreditation Council for Services to People with Disabilities), and others.

Sociodemographic Data

- Background Information
  - Identification- 5 questions
  - Support Level for Adaptive, Behavioral, Mental Health, Medical, Legal, or Day Program Areas
  - Legal Issues- 3 questions
  - Medical and Mental Health- 7 questions
  - Day Supports and Integration- 5 questions
  - Type of Residential and/or Work/Day Service
  - Supervision Level
- Satisfaction- 23 questions
- Personal Security- 2 questions
- Relationships- 16 questions
- Talents and Personal Goals- 8 questions
- Self-esteem- 8 questions
- Decision-Making- 19 questions
- Community Inclusion-58 questions
- Rights Restrictions- 15 questions
- Community Accessibility- 11 questions

Data Availability

Data collection forms are available, as are aggregate data reports

Contact

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Connecticut Automated Mental Retardation Information System (CAMRIS)

State

Connecticut

Population/Purpose

CAMRIS contains demographic data on all Department of Mental Retardation clients (12,000 clients state-wide) on a mainframe computer. Regional offices also maintain data on their caseloads.

Demographic data is not always current. The system has the capacity for diagnosis and service needs, however, since that information is not used regularly it tends not to be current. Information about placements, type of residence, funding sources, and cost are used frequently and are therefore very reliable.

The system is currently being revised to determine if there are fields that can be eliminated or if others should be added.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
  - Severe
  - Moderate
  - Mild
  - Not retarded
  - Not determined
- Related Conditions: diagnosis is DSM III-R and ICD 9
  - Autism
  - Cerebral Palsy
  - Spina Bifida
  - Other
- Sensory
  - Vision
  - Hearing
- Medical Conditions
  - Allergies
  - Feeding Method: i.e., tube diet
- Medications
- Functional Characteristics
  - Mobility
  - Eating: diet only
- Communication Level
- Problem Behavior
- Psychiatric Diagnosis: DSM III-R

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Community training home
- Independent living
- Supported living
- Family/Relative home
- Residential school
- Waiting for residential services

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only

Other Services Received

- Case management
- Vocational
- Habilitation
- Physical therapy
- Occupational therapy
- Speech therapy
- Transportation
- Psychological/Psychiatric services

Costs of Services

- Residential/Personal Assistance
- Private group homes
- Community training homes
- Nurseries
- Residential schools
- Supported living
- Vocational
- All private programs
- Medical Services
- Number of state staff by program by cost

Data Availability

Access is limited by security and passwords. Regions control access within their region. Central office has state-wide access. Numerous ad hoc reports are produced, as well as regular monthly, quarterly, and annual reports. Data collection forms are available at various levels.

Contact

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E. Hartford, CT 06108
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Patient Accounting Client Tracking (PACT)

State

Delaware

Purpose/Population

The PACT contains background information on all clients assigned to the Division of Mental Retardation (residents of state-operated and non-state-operated, but state-contracted services). Information includes case history (such as medical exams, doctors, family background, past and current residence), Medicaid status, and insurance.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
  - Other Conditions
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Other Limitations
- Communication Skills
- Communication Mode
- Problem Behavior
- Psychiatric Diagnosis

Residential Service Types Included

- State institution
- State group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Waiting for residential services

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only

Other Services Received

- Case Management
- Vocational
- Habilitation
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Transportation
- Psychological/Psychiatric Services

Cost of Services

- Residential/Personal Assistance
- Vocational

Data Availability

Personal qualifiers need to be removed from the data. Reports are mostly in-house, but data collection forms are available.

Contact

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Allocation, Budget, and Contract (ABC) Control System

State

Florida

Population/Purpose

The ABC System tracks demographic characteristics and services received for all developmentally disabled clients of the Department of Health and Rehabilitation Services, Developmental Services Division.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
  - Other
- Sensory
  - Vision
  - Hearing
  - Other sensory deficit
- Medical Conditions
  - Only yes/no response to "Is medically complex" and "mild to critical for chronic health."
- Medications
- Chemical/behavioral intervention
- Functional Characteristics
  - Self-preservation
  - Mobility
  - Self-care
  - Economic self-sufficiency
  - Self-direction
  - Independent living
- Ambulation
- Problem Behavior
  - Property destruction
  - Self-abuse
  - Emotional disturbance

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Foster home
- Supported living
- Family/Relative home
- Mental health group home
- Psychiatric hospital
- Other residential types
- Waiting for residential services

Residential Services: Funding Sources

- ICF-MR
- Home and Community Based Services (HCBS) Waiver
- Community Supported Living Arrangements (CSLA)
- State-only

Other Services Received

- Case management
- Vocational

- Supported employment
- Habilitation therapy
- Physical therapy
- Occupational therapy
- Speech therapy
- Psychological/Psychiatric services
- Respite
- Behavioral programming
- Recreational therapy
- Medical/Dental services
- Diagnosis and evaluation
- Supplies and equipment
- Parent training
- Homemaker
- Personal assistance
- Family subsidy

Costs of Services

Costs available for any services listed above for non-institutional persons only

Data Availability

Data must be stripped of client identifiers except on approval of Secretary of the Department. Reports are not available. Data collection forms are available but they are out-of-date.

Contacts

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Developmental Disabilities Information System (DDIS)

State

Hawaii

Population/Purpose

The DDIS is the main database of Hawaii's Developmental Disabilities Division. It is used for case management, service and program planning, and state and federal reporting. The DDIS consists of three major files: Client Demographic, Client Profile, and Client Service Tracking. The Client Demographic file is a basic demographic profile. The Client Profile is used to track client progress and contains information on current functioning level, level of mental retardation, and challenging behaviors. The Client Demographic and Client Profile files together are used for program planning on a local and state-wide basis. The Client Service Tracking file is a chronological record of the services a client is receiving and has received, including residential movement.

Sociodemographic Data

- Client Demographic File
  - Age
  - Gender
  - Race/Ethnicity
  - Marital Status
  - Current Residence
  - Insurance
  - Religion
  - Family members and relationship
- Client Profile File
  - Level of Mental Retardation
  - Other Related Conditions
  - Sensory
    - Vision: blind or visual impairment
    - Hearing: deaf or hearing impairment
  - Medical Conditions
    - Congenital anomalies
    - Significant health problem(s)
    - Genetic component
    - Major surgery
    - Seizures
    - Motor problem
  - Medications
    - Seizure
    - Cardiac
    - Psychotropic
  - Functional Abilities/Limitations
    - Toileting
    - Dressing
    - Mobility
    - Eating
    - Bathing
    - Personal hygiene
    - Home management
    - Leisure
    - Employment
    - Self-direction: initiative
    - Responsibility
  - Communication
    - Expressive
    - Receptive
  - Problem Behavior

Residential Service Types Included

- Client Demographic File
  - Nursing home
  - State institution
  - Nonstate institution
  - State group home

- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Own home

Other Services Received

- Client Tracking File
- Case management
- Vocational
- Habilitation
- Other

Data Availability

While all of the data in the DDIS is confidential, reports are available, as are the data collection forms.

Contact

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Inspection of Care-Medicaid (IOC-Medicaid)

State

Idaho

Purpose/Population

The IOC-Medicaid is used to re-verify Level of Care for all persons in nursing homes and ICFs-MR. Done by field staff. Pre-Admission Screening and Annual Resident Review (PASARR) is built into Inspection of Care/Level of Care review.

Sociodemographic Data

- Age
- Gender
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Abilities/Limitations
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
- Communication
  - Skills
  - Mode
- Problem Behavior
- Psychiatric

Residential Service Types Included

- Nursing home
- State institution
- Nonstate group home

Data Availability

Data and reports are confidential.

Contact

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Acting Supervisor-Medicaid Policy
Department of Health and Welfare
Bureau of Medicaid Policy and Reimbursement
Statehouse Mail
Boise, ID 83720
Phone (208) 334-5795 Fax (208) 334-0657

Developmental Disabilities Profile (DDP)

State

Kansas (see also New York)

Population/Purpose

The DDP is used in initial screening to make a determination of disability level for ICF-MR care. It is also used in ICFs-MR to help establish reimbursement levels and in establishing limits paid for certain services in the HCBS waiver.

Sociodemographic Data

- Age
- Gender
- Level of Mental Retardation
- Related Conditions
  - Learning Disability
  - Undetermined developmental disability
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
  - Other neurological impairment
- Sensory
  - Vision
  - Hearing
- Medical Conditions
  - Respiratory
  - Cardiovascular
  - Gastrointestinal
  - Genito-urinary
  - Neoplastic disease
  - Neurological disease
  - History of seizures
- Prescription Medication
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Showering
  - Making bed
  - Cleaning room
  - Doing laundry
  - Shopping
  - Telephone usage
- Communication
  - Receptive language skills
  - Expressive language skills
- Problem Behavior
- Psychiatric Diagnosis

Clinical Services Received

- Psychologist
- Psychiatrist
- Speech and hearing pathologist
- Physical therapist
- Occupational therapist
- Physician
- Nurse
- Social Worker

Residence Types Included

- Nursing home
- State institution
- Nonstate institution
- Family/Relative home
- Other residence
- Waiting for residential services

Data Availability

Data is accessible if stripped of individual names. An annual report to plot demographics is produced. Data collection forms are available.

Contact

Larry Sherraden
Community Programs
Department of Social and Rehabilitation Services
State Office Building, 5th Floor
Topeka, KS 66612
Phone (913) 296-6140 Fax (913) 296-6142

Kansas Rehabilitation Information System (KRIS)

State

Kansas

Population/Purpose

The KRIS contains data on all persons with mental retardation/developmental disabilities receiving residential or day habilitation services, or waiting for services. The KRIS is a demographic data system and contains information on who the persons with mental retardation/developmental disabilities are, where they live, what services they receive, or what services they are waiting to receive.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity

Residential Service Types Included

- State institution
- Nonstate institution
- Semi-independent living
- Supported living
- Other residence type
- Waiting for residential services

Other Services Received

- Vocational
- Habilitation
- Other

Data Availability

Data is accessible if stripped of individual names. Reports are available on both active clients and those on waiting lists. KRIS is mostly electronic, so data collection forms are not available

Contact

Larry Sherraden
Community Programs
Department of Social and Rehabilitation Services
State Office Building, 5th Floor
Topeka, KS 66612
Phone (913) 296-6140 Fax (913) 296-6142

Community Mental Health Decision Support System (CMHDSS)

State

Michigan

Population/Purpose

The CMHDSS is the minimum data set for client demographic information required of Community Mental Health Boards for the identification of service recipients. The Michigan Department of Mental Health is currently in the process of revamping its management information system to collect from the 55 distributed community-based service agencies common demographic service and financial information across the spectrum of community-based programs.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Principal and all other diagnoses from DSM III-R
- Duration of mental health related condition
- Education
- Employment
- Total gross household income
- Principal source of income
- Eligibility (State Disability Act, SSI, SSDI)

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Other residence

Residential Services: Funding Sources

- ICF-MR
- Other Medicaid
- State-only

Other Services Received

- Psychological/Psychiatric Services

Data Availability

Data collection forms are available from CMH Boards. Summary data reports are available from the contact person.

Contact

Susan Lawther
Deputy Director, Bureau of Community Mental Health Services
Department of Mental Health
Northern Area Office
701 S. Elmwood, Suite 15
Traverse City, MI 49684
Phone (616) 941-7405 Fax (616) 941-0283

Client Tracking/Management Support Information Systems

State

Minnesota

Population/Purpose

There are five major systems which comprise the Client Tracking/Management Support Information Systems. Two of these are especially applicable to residential services.

The DD Provider/Client/Screening Tracking System is designed to serve a variety of professionals in the field of developmental disabilities (e.g., case managers, program managers, supervisors, policy analysts). This system links databases of current group facility residents with the two client screening/diagnostic databases (the MR Screening Database and the Quality Assurance and Review Database), several provider/facility databases, and a corporate ownership database. This database contains client-specific history and level of functioning information, cost and rate data associated with specific service providers, aggregate profiles of facility and group home residents, and information about corporate entities and the facilities that they manage. Data sources are updated bi-weekly, monthly, and annually depending on the frequency of critical changes in the individual data sources.

The Waiver Allocation and Bed Decertification Tracking System is designed to facilitate management of several Title XIX waiver programs and demonstrations: the original Home and Community Based Services waiver for persons with mental retardation and related conditions (MR/RC), the Enhanced Waivered Services Fund (EF) for persons who are relocating from regional treatment centers to the community, and the Alternative Care Services Waiver (ACS) for persons who are relocating from nursing homes to the community in accordance with PASARR recommendations, and other, smaller waiver demonstrations. This system maintains and displays county-specific and client-specific records of waiver utilization, by waiver type and fund. It also monitors the decertification of ICFs-MR beds in both regional treatment centers and community-based facilities.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Primary/Secondary/Tertiary Diagnosis (ICD-9 Codes)
  - Mental Retardation
    - Mild
    - Moderate
    - Severe
    - Profound
    - Unspecified
  - Cerebral Palsy
  - Epilepsy
  - Psychosis
  - Autism
- Medical needs
- Seizures
- Medications
- Sensory
  - Vision
  - Hearing
- Communication
- Mobility
- Self-preservation
- Level of Supervision needed
- Problem Behavior
- Independent Living Skills: level of care needed
  - Self-care
  - Toileting
  - Household Management
  - Money Management

- Community Living
- Leisure and Recreation
- Risk status

Residential Service Types Included: Current and Planned

- Skilled nursing facility
- Intermediate care facility
- ICF-MR State hospital
- ICF-MR Community
- Licensed board and lodging
- Uncertified board and lodging
- Own home
  - independent
  - supervised <24 hours/day
  - supervised 24 hours/day
- Respite care facility
- Family/relative home
- Foster family
- Other

Support Services Received/Planned

- Case management
- Homemaker services
- Respite care (not in a ICF-MR bed)
- In-home family support
- Minor physical adaptations
- Supported living arrangement-child
- Supported living arrangement-adult
- Family subsidy
- Semi-independent living services (SILS)
- Respite care (ICF-MR State hospital)
- Respite care (ICF-MR Community)

Day Services Received/Planned

- Adult day habilitation
- Preschool program (home)
- Preschool program (center)
- Elementary school program (public)
- Secondary school program (public)
- Transition program
- Work activity (long-term)
- Sheltered employment (long-term)
- Protected work station

Special Support Services Needed

- Specialized medical services
- Physical therapy
- Occupational therapy
- Communication training/Speech therapy
- Special transportation
- Behavior management program
- Infant stimulation

Data Availability

Although data is confidential, reports and data collection forms are available.

Contact

Jim Franczyk
Research, Evaluation, and Planning Director
Division for Persons with Developmental Disabilities
Minnesota Department of Human Services
444 Lafayette Rd.
St. Paul, MN 55155-3825
Phone (612) 296-2171 Fax (612) 297-4692

Montana Individual Information System (MIIS)

State

Montana

Population/Purpose

The MIIS is the primary informational relational database for services and finances. It provides tracking of individuals, including those on waiting lists. It is also used for planning and budgeting and to fulfill legislative requests and federal data requirements.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Other
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Other
- Communication
  - Skills
  - Mode
- Problem Behavior
- Psychiatric Diagnosis

Residential Service Types Included*

- Nursing home
- State institution
- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Waiting for residential services

*The MIIS uses the ICAP for most of this information. Supported living-as a service, not a residence type-can be obtained from another portion of the MIIS. State is assuming that the ICAP will be less useful in the future as more and varied living arrangements are developed.

Residential Services: Funding Sources

- ICF-MR: State institution is the only ICF-MR
- HCBS
- State-only

Other Services Received

- Case management
- Vocational
- Habilitation
- Physical Therapy, Occupational Therapy, and Speech Therapy: all combined

- Transportation
- Psychological/Psychiatric Services
- Other

Cost of Services

Cannot readily access cost information for services not provided by the Developmental Disabilities Division. Requires matching two databases which is done on request. Medical costs are only those paid through Medicaid. We have never matched data from education although the database (MIIS) was designed with that capability. No way was found to be compatible with "health" databases.

Data Availability

Signed releases are obtained upon entrance into services. Information is distributed specific to an individual on a need/right to know basis. Reports and data collection forms are available.

Contact

Janice Frisch, Management Operations Bureau Chief
Developmental Disabilities Division
Department of Social and Rehabilitation Services
PO Box 4210
Helena, MT 59604
Phone (406) 444-2995 Fax (406) 444-0230

Client Option * Oriented Profile (CO-OP)

State

New Mexico

Population/Purpose

The COOP contains information on all persons who have applied for and are waiting for services and all persons actively receiving services through any and all developmental disabilities providers.

Sociodemographic Data

- Age
- Gender
- Marital Status
- Race/Ethnicity
- Social Security Number
- Preferred Geographical Area
- Preferred Provider
- Contact Person/Address
- Court Appointed Legal Guardian (if applicable)
- Adaptive Level of Functioning
- Dually Diagnosed
- Mental Retardation Severity
- IQ Score
- ICAP Score
- Related Conditions
  - Cerebral Palsy
  - Autism
  - Seizure Disorder
  - Learning Disability
  - Neurological Impairment
- Speech Impairment
- Sensory
  - Vision Impairment
  - Hearing Impairment
- Physical Aids/Medications required
- Chronic Medical Impairment
- Mobility Impairment
- Behavioral/Emotional Impairment
- Extreme Maladaptive Behavior
- Medical Level of Care
- Most Recent IPP/IFSP

Case Status

- Referral
- Waiting List
- Active
- Respite Care
- Extended Leave
- Outreach
- Discharged/Closed

Current Services Provided

- Infant Family Services
- Preschool
- Service Coordination
- Personal and Social Support
- Work Services
- Respite Services
- Family Living
- Supervised Living
- Supported Living
- Individual
- Family-based
- Group
- Education/Training Programs
- Public Schools
- Competitive Employment
- Supported Employment
  - Individual
  - Group

- Chore Services
- Behavioral Support
- Post-Service Monitoring
- Speech Therapy
- Physical or Occupational Therapy
- Psychosocial Rehabilitation
- Inpatient Psychiatric Hospital Services
- Homemaker/Home Health Aide
- Nursing
- Medical
- Nutrition
- Personal Care
- Counseling
- Specialized Care Facility Services
- Dental Care
- Prosthetic Services
- Environmental Modifications
- Mobility Training
- Assistive Technology Devices and Services
- Vision Services
- Audiology
- Transportation Services
- Other
- No Other Services Needed

Funding Sources for Services

- State General
- Division of Vocational Rehabilitation
- Medicaid Waiver
- Medicaid/Medicare
- Supplemental Security Income (SSI)
- Other Public Assistance
- Social Security Administration (SSA)
- Veteran's Administration (VA)
- Bureau of Indian Affairs (BIA)
- Section 8 Rental Assistance
- Parent/Guardian Payment
- Client Payment
- Third Party Payor
- ICF-MR
- Aid to Families with Dependent Children (AFDC)
- State Education Funds
- Federal Education Funds (94-142)
- Federal Early Intervention Funds (99-457, Part H)
- Early Periodic Screening Diagnosis and
- Treatment (EPSDT)
- Other Than Above
- Unknown

Specialized Services

- Evaluation/Assessment
- Nursing Facility Services
- Behavioral Support Services
- Personal Care/Independent Living Skills
- Advocacy
- Guardianship
- Mobility Skills
- Legal Assistance
- Physical/Occupational Therapy
- Speech Therapy/Communication
- Audiology
- Medical/Dental
- Visual Related Habilitation
- Psychotherapy
- Family Counseling/Parent Training
- Other

Current Residential Setting

- Private Home
- Independent Living
- Family Living
- Supported Living
- Boarding Home
- Nursing Home
- Supervised Living
- ICF-MR (15 beds or less)
- ICF-MR (more than 15 beds)
- Hospital

- Private Institution
- Other Than Above
- Unknown
- None
- Needed Residential Setting

Data Availability

Although data from the CO-OP is confidential, reports and data collection forms are available.

Contact

Claude Perry
Department of Health
Developmental Disabilities Division
Centralized Services Team
6620 Gulton Court NE
Albuquerque, NM 87109
Phone (505) 841-8765 Fax (505) 841-8790

Tracking and Billing System (TABS)

State

New York

Population/Purpose

The TABS is the main Office of Mental Retardation and Developmental Disabilities (OMRDD) system. It includes all persons with mental retardation/developmental disabilities receiving residential or non-residential services or in need of such services (a total of 160,000 people). TABS has three main subsystems: the Developmental Disabilities Profile (DDP), Needs Assessment, and Registration

The Developmental Disabilities Profile (DDP) is used to gather disabilities, strengths, needs, and other information historically for individuals served by OMRDD in state-operated, voluntary, and other proprietary settings. Data is collected from screening units, residential units, and non-residential units by clinicians and other professional staff during the client's days. The DDP is used to monitor clients' progress and needs, set rates, and determine staffing ratios.

The Needs Assessment is used to gather needs and other information historically for individuals served by OMRDD in state-operated, voluntary, and other proprietary settings. Data is collected from screening units, residential units, and non-residential units by clinicians and other professional staff. The Needs Assessment allows the capability to track and report information about client characteristics, residential placement needs, adult day program needs, family support, and other needs.

Registration is used to gather demographic and other information historically for individuals served by OMRDD in state-operated, voluntary, and other proprietary settings. Data is collected from screening units, residential units, and non-residential units by clinicians and other professional staff during the client's days. Allows registration of clients into Developmental Disabilities Service Offices (DDSOs). Fields maintained include, but are not limited to: Client name, Address, Location, Legal Status, Diagnosis, Date of Birth, Social Security Number, Medicare number and aliases.

Sociodemographic Data

- Age
- Gender
- Level of Mental Retardation
- Related Conditions
  - Learning Disability
  - Undetermined developmental disability
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
  - Other neurological impairment
- Sensory
  - Vision
  - Hearing
- Medical Conditions
  - Respiratory
- Cardiovascular
- Gastrointestinal
- Genito-urinary
- Neoplastic disease
- Neurological disease
- History of seizures
- Prescription Medication
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Showering
  - Making bed
  - Cleaning room
  - Doing laundry
  - Shopping
  - Telephone usage

- Communication
  - Receptive language skills
- Expressive language skills
- Problem Behavior
- Psychiatric Diagnosis

Clinical Services Received

- Psychologist
- Psychiatrist
- Speech and hearing pathologist
- Physical therapist
- Occupational therapist
- Physician
- Nurse
- Social Worker

Residential Service Types Included

- Nursing home*
- State institution
- Nonstate institution
- State group home
- Nonstate group home*
- Foster home*
- Semi-independent living
- Supported living
- Family/Relative home
- Other
- Waiting for residential services

* limited data regarding the type of home are collected; only in special circumstances is identifying (address) data collected

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only

Other Services Received

- Case management
- Vocational
- Habilitation
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Transportation
- Psychological/Psychiatric Services
- Physician
- Day treatment
- Other

Data Availability

Data is confidential, but reports and data collection forms are available.

Contact

Mary Edmonds, Manager
Office of Mental Retardation and Developmental Disabilities
Information Support Services
800 N. Pearl Street, 2nd Floor
Albany, NY 12204
Phone (518) 473-9205 Fax (518) 473-9593

Ohio People with Disabilities (OPD)

State

Ohio

Population/Purpose

OPD contains demographic and service information on all persons receiving state-paid residential services, including residents of ICFs-MR, state Developmental Centers, county board services, nursing facilities, and waiver recipients, and persons waiting for such services.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
- Sensory Status
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Characteristics
  - Mobility
- Communication Skills
- Communication Mode
- Problem Behavior

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Other residence
- Waiting for residential services

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only

Other Services Received

- Case management
- Vocational

Data Availability

Reports and data collection/aggregation forms are available

Contact

Donna Wood, Manager of Systems Development
Ohio Department of Mental Retardation and Developmental Disabilities
30 E. Broad St., Room 1310L
Columbus, OH 43215
Phone (614) 466-2201

Developmental Disabilities Quality Assurance Questionnaire

State

Oklahoma

Population/Purpose

This questionnaire has three parts: an interview with the primary caregiver, a consumer satisfaction interview, and a qualitative site assessment. Changes in independence, integration, productivity, and satisfaction are tracked longitudinally to measure quality of life enhancement. Assessments are completed annually on approximately 3,700 individuals at a variety of residential sites throughout Oklahoma. The assessment instrument was adopted from the instrument used by the Temple University Affiliated Program to monitor consumer outcomes during the closure of Pennhurst State School and Hospital and the relocation of all residents into community based service options.

Yearly reports of the survey research are made to the Oklahoma Quality Assurance Advisory Council. Represented on the Council are primary consumers, family members, service providers, Department of Human Services staff, the Oklahoma Developmental Disabilities Council, research staff, and consultants. Survey reports are disseminated to provider agencies who may use the results to improve service quality.

Sociodemographic Data

- Age
- Gender
- Race
- Type of residence
- Level of Retardation
- Other disabilities
  - Visual impairment
  - Hearing impairment
  - Autism
  - Cerebral palsy
  - Physical disabilities
  - Mental illness
  - Feeding tube
  - Tracheostomy
- Residential history
- Adaptive equipment needs
- Adaptive skills
- Problem behavior
  - Frequency and severity
- Medical needs
  - Seizures
  - Medication usage
  - Illness history: asked only for those persons placed in nursing homes
- Home/Living Arrangements/Financial
- Information/Social Interactions
- Civil and Citizenship Activities
- Service Planning/Delivery

Consumer Interview

Questions are answered in private by the client. For example:
"Do you like living here or not like living here?"
"Do you like the people who work with you or not like them?"
"Do you visit your family often?" and
"If you had one wish, what would you wish for?"

Physical Quality

Questions to be completed for the smallest living unit for each facility

- External

- Room by room
- Variation in design of residents' rooms/apartments
- Personalization of residents' rooms/apartments
- Overall physical pleasantness of the facility
- Overall rating
- Quality/Quantity of food
- Staff-consumer/consumer-staff relations
- Consumer-consumer interactions
- Staff expectations of consumers regarding growth
- Handicap accessibility
- Are the clients happy here?

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- Group home
- Foster care
- ICF
- Independent living
- Semi-independent living
- Supported living
- Incarcerated
- Mental health facility
- Family/relative home

Data Availability

Questionnaires and summary reports are available

Contact

Patricia Bell
Department of Sociology
Oklahoma State University
Stillwater, OK 74078-0395
Phone (405) 744-6104 Fax (405) 744-5780

Consumer Process Monitoring System (CPMS)

State

Oregon

Population/Purpose

The CPMS was implemented by the Mental Health and Developmental Disability Services Division (MHDDSD) during the 1981-83 biennium. CPMS tracks primarily clients in residential, vocational, and related case management. It documents that consumers are being served in accordance with State laws and contract requirements. CPMS documents contract utilization and provides financial information for auditing contract performance. The MHDDSD maintains a registry on CPMS of all provider agencies and programs which (1) the MHDDSD is required by Oregon Revised Statutes to certify, license, and approve; (2) receive MHDDSD funds to perform student services under contract with the MHDDSD; or (3) receive MHDDSD funds to perform consumer services under a subcontract with MHDDSD omnibus or program area contractor. Providers meeting any of these registration criteria must report consumer information through CPMS.

Sociodemographic Data

- Age
- Gender
- County/State/Country of Residence
- Race/Ethnicity
- Related Conditions
  - Cerebral Palsy
  - Epilepsy
- Motor Dysfunction
- Behavior Dysfunction
- Communication Dysfunction
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications

Residential Service Types Included

- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Relative foster home
- Non-relative foster home
- Own home
- Parent/Relative home
- Friends or others home
- Skilled nursing facility
- ICF (Semi-skilled)
- Satellite apartment
- Room and board
- Semi-independent or independent living
- Supported living
- Waiting for residential services

Other Services Received

- Case management
- Vocational
- Habilitation
- Transportation
- Homemaker
- Inhome support
- Physical adaptations to the home
- Respite care
- Special diet/adaptive equipment

Data Availability

Consumer information reported to the MHDDSD through CPMS in confidential and protected by law and procedural safeguards. No person or agency other than authorized personnel can gain access to confidential consumer information on CPMS. Reports and data collection forms are available.

Contact

Sean McMullen, Data Coordinator
Department of Human Resources/Mental Health and Developmental Disabilities Services Division/Office of Developmental Disabilities Services
2575 Bittern St. NE
Salem, OR 97310
Phone (503) 945-9799 Fax (503) 373-7274

Facility Client Tracking (FACT)

State

Pennsylvania

Population/Purpose

An integrated mental retardation demographic/diagnostic/census system for all residents of state institutions.

Sociodemographic Data (* based on results of individual diagnoses from AAMR Manual)

- •Age
- •Gender
- •Race/Ethnicity
- •Level of Mental Retardation*
- •Related Conditions*
  - •Autism
  - •Cerebral Palsy
  - •Epilepsy
  - •Spina Bifida
  - •Other
- •Sensory*
  - •Vision
  - •Hearing
- •Medical Conditions*
- •Problem Behavior*
- •Psychiatric*

Residential Service Types Included

- •State institution

Residential Services: Funding Sources

- •ICF-MR
- •State-only

Other Services Received

All persons in the system receive case management
Services are identified in other databases.

Costs of Services

Costs are collected on other financial reports

Data Availability

Data is collected on an individualized basis. All data are available, provided no person can be identified. Examples of identifying data are: name, address, responsible persons, some case numbers, etc. Data collection forms are available.

Contact

Michael J. Toth, Mental Retardation Program Specialist
Office of Mental Retardation
Pennsylvania Department of Public Welfare
PO Box 2675
Harrisburg, PA 17105-2675
Phone (717) 787-8841 Fax (717) 787-6583

Community Residential Facilities (CRF)

State

Pennsylvania

Population/Purpose

Tracks those people who are living in community residential settings, those people receiving Home Based Services, and those people receiving services in the nonstate-operated ICF-MR program. Does not include respite care.

Sociodemographic Data (* based on results of individual diagnoses from AAMR Manual)

- •Age
- •Gender
- •Race/Ethnicity
- •Level of Mental Retardation*
- •Sensory*
- •Vision
- •Hearing
- •Medical Conditions*
- •Psychiatric*

Residential Service Types Included (includes immediately prior and present living arrangements)

- •Nonstate institution
- •State group home
- •Nonstate group home
- •Foster home
- •Semi-independent living
- •Supported living
- •Family/Relative home

Residential Services: Funding Sources

- •ICF-MR
- •HCBS

Other Services Received

All persons in the system receive case management

Costs of Services

Costs are collected on other financial reports

Data Availability

Data is collected on an individualized basis. All data are available, provided no person can be identified. Examples of identifying data are: name, address, responsible persons, some case numbers, etc. Data collection forms are available.

Contact

Michael J. Toth, Mental Retardation Program Specialist
Office of Mental Retardation
Pennsylvania Department of Public Welfare
PO Box 2675
Harrisburg, PA 17105-2675
Phone (717) 787-8841 Fax (717) 787-6583

Service Record Database

State

South Dakota

Population/Purpose

The Service Record is an individual based database. It includes residential, day program, and other service information (case management, respite, etc.). The planned outcome of this database is to ensure accurate individual records are kept and payments are provided to agencies in a timely manner.

Sociodemographic Data

- Age
- ICAP Service Score/Date
- Prior residence
- Prior day program

Residential Service Types Included

- With parents or relatives
- Foster home
- Independent
  - regular home-based services
  - monitoring
- Room and board without personal care
- Supervised apartment
- Certified residential facility

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only
- Other

Other Services Received

- Case management
- Integrated vocational
- Integrated residential
- Speech, hearing, and language
- Medical equipment and drugs
- Other medical
- Respite

Data Availability

Data is confidential, but might share database without specific client identifying information. Reports and data aggregation forms are available.

Contact

Ed Campbell, Senior Data Analyst
Human Services/Developmental Disabilities
Department of Human Services, Division of Developmental Disabilities
Hillsview Properties Plaza, East Highway 34
500 East Capital
Pierre, South Dakota 57501
Phone (605) 773-3438 Fax (605) 773-5483

Inventory for Client and Agency Planning (ICAP)

State

South Dakota (see also Utah and Wyoming)

Population/Purpose

The ICAP is administered annually for all recipients of residential and day services. The ICAP is the client-related part of the tool used to determine eligibility for ICF-MR and/or HCBS.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Other
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Other
- Communication
  - Skills
  - Mode(s) used
- Problem Behavior
- Psychiatric

Residential Service Types Included

- Nursing home
- State institution
- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home

Other Services Received

- Case management
- Vocational
- Speech Therapy
- Other Services

Data Availability

Data is confidential, but might share database without specific client identifying information. South Dakota is interested in sharing data with other states which utilize the ICAP. Reports and data aggregation forms are available.

Contact

Ed Campbell, Senior Data Analyst
Human Services/Developmental Disabilities
Department of Human Services, Division of Developmental Disabilities
Hillsview Properties Plaza, East Highway 34
500 East Capital
Pierre, South Dakota 57501
Phone (605) 773-3438 Fax (605) 773-5483

Client Assignment and Registration System-Mental Health and Mental Retardation (CARE-MHMR)

State

Texas

Population/Purpose

The CARE-MHMR includes all recipients of Texas Department of Mental Health and Mental Retardation services.

Sociodemographic Data

- Level of Mental Retardation
- Sensory
  - Vision
  - Hearing
- Communication
  - Skills
  - Mode
- Client Needs
  - Structured Programs
  - Specialized Therapies
  - Health Care Services
  - Needed Residential Characteristics
    - Location and characteristics of physical plant
    - Supervision
    - Health care availability
  - Restrictiveness of Environment
- Health Status
- Problem Behavior
- Functional Characteristics
  - Mobility
- Prosthetics Usage
- Recommended Movement
- Client's Environmental Preference
- Parent's/Guardian's Environmental Preference
- Least Restrictive Placements
- Community Support Services
- Legal Status
- Competency Status
- Family Contact

Residential Service Types Included

- State institution
- Nonstate institution
- State group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Other residence

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only

Other Services Received

- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Psychological/Psychiatric Services
- Other

Data Availability

Data is confidential and reports are not available.

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Level of Care-3650

State

Texas

Population/Purpose

The Level of Care-3650 is used to screen all recipients of Medicaid (ICF-MR and HCBS) services.

Sociodemographic Data

- Age
- Gender
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Functional Characteristics
  - Toileting
  - Dressing
  - Mobility
  - Eating
- Communication
  - Skills
  - Mode
- Problem Behavior

Residential Service Types Included

- State institution
- Nonstate institution
- State group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home

Residential Services: Funding Sources

- ICF-MR
- HCBS

Other Services Received

- Vocational
- Habilitation
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Psychological/Psychiatric Services

Data Availability

Data is confidential and reports are not available.

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Unified Social Service Delivery System-
Division of Services for People with Disabilities (USSDS-DSPD)

State

Utah

Population/Purpose

The USSDS-DSPD is a state-wide mainframe, accessible from personal computers across the state. It contains information on persons receiving private and public residential and day treatment services and persons waiting for services, however it does not include persons in ICFs-MR. It also includes client records on intake; eligibility; what services they are receiving, have received, and are waiting to receive; and demographic information.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Spina Bifida
  - Other
- Sensory
  - Vision
  - Hearing

Residential Service Types Included

- Nonstate institution
- State group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Waiting for residential services

Residential Services: Funding Sources

- State-only

Other Services Received

- Case management
- Vocational
- Habilitation
- Transportation
- Psychological/Psychiatric Services
- Other

Cost of Services

- Residential/Personal Assistance
- Vocational
- Other

Data Availability

Data is confidential but reports are available.

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Inventory for Client and Agency Planning (ICAP)

State

Utah (see also South Dakota and Wyoming)

Population/Purpose

The ICAP is used for determining eligibility, i.e. identifying levels of adaptive behavior and determining rates for service. Providers are paid according to the individual's needs as defined partially by the ICAP.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Other
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Other
- Communication
  - Skills
  - Mode(s) used
- Problem Behavior
- Psychiatric

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Waiting for residential services

Other Services Received

- Case management
- Vocational
- Habilitation
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Transportation
- Psychological/Psychiatric Services
- Other Services

Data Availability

Data is confidential but reports are available.

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Quarterly Services Report (QSR)

State

Vermont

Population/Purpose

The QSR contains data on services provided for all people who receive services through community mental retardation and mental health agencies that are funded publicly (by the Vermont Department of Mental Health and Mental Retardation).

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Problem Behavior
- Psychiatric Diagnosis
- Zip Code
- Type of Residence
- Nursing home
- Nonstate group home
- Foster home
- Supervised apartment
- Independent living
- Semi-independent living
- Family/Relative home

Residential Service Types Included (counted only for those people whose services are provided by the agency)

- ICF-MR
- Nonstate group home
- Supervised apartment
- Independent living

Residential Services: Funding Sources

- ICF-MR
- HCBS
- State-only

Other Services Received

- Adult Day Health
  - Social/Recreation
  - Physical Therapy
  - Occupational Therapy
  - Speech
  - Other Psychotherapy
  - Psychiatric Transportation
- Case Management: Service Coordination/Monitoring (includes IPP and related)
- Companion
- Crisis
- Level A Habilitation
  - Self-help/Basic Life Skills
  - Physical Therapy
  - Occupational Therapy
  - Speech
  - Other Psychotherapy
  - Psychiatric Transportation
- Level B Habilitation
  - Self-sufficiency Assistance and Training
  - Physical Therapy
  - Occupational Therapy
  - Speech
  - Other Psychotherapy

- •Psychiatric Transportation
- •Personal Care
- •Residential Habilitation
  - •Training and Assistance
  - •Environmental Modification
- •Respite Care
- •Supported Employment
  - •Supervision and Training
  - •Transportation

Data Availability

Data is confidential. Aggregate reports are available, as are data collection forms.

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Division of Developmental Disabilities-
Management Information System (DDD-MIS)

State

Washington

Population/Purpose

The purpose of the DDD-MIS is to collect data related to all clients of the Division of Developmental Disabilities (DDD). DDD clients have met eligibility criteria as set forth in state statute and applied for services. Included in this database are demographic, eligibility, residential, day program, significant other, and other services data. It is often considered a client tracking system. This database allows for the production of reports on many aspects of the client population for division staff and other interested parties.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Spina Bifida
- Sensory
  - Vision
  - Hearing

Residential Service Types Included

- Nursing home
- State institution
- Nonstate institution
- State group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home
- Other Residence
- Waiting for residential services

Cost of Services

- Medical Services
- Family Support Services

Data Availability

Data is confidential, but reports are available

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Inventory for Client and Agency Planning (ICAP)

State

Wyoming (see also South Dakota and Wyoming)

Population/Purpose

The ICAP is administered at intake and yearly for all recipients of residential and day treatment services. The ICAP is used for individual-level program planning, case management, and tracking; and service planning. State is currently investigating using ICAP to help set rates for residential services. Rates are currently set upon examination by the State DD staff of each individual plan of care.

Sociodemographic Data

- Age
- Gender
- Race/Ethnicity
- Level of Mental Retardation
- Related Conditions
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Other
- Sensory
  - Vision
  - Hearing
- Medical Conditions
- Medications
- Functional Characteristics
  - Self-preservation
  - Toileting
  - Dressing
  - Mobility
  - Eating
  - Other
- Communication
  - Skills
  - Mode(s) used
- Problem Behavior
- Psychiatric

Residential Service Types Included

- Nursing home
- State institution
- Nonstate group home
- Foster home
- Semi-independent living
- Supported living
- Family/Relative home

Other Services Received

- Case management
- Vocational
- Habilitation
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Transportation
- Psychological/Psychiatric Services
- Other Services

Data Availability

Data is confidential, but reports are available.

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TABLES

TABLE 1: Individual Characteristics

State	Data Base	Age	Gender	Race/ Ethnicity	Level of MR	Autism	CP	Epilepsy	Spina Bifida	Vision	Hearing	Medical Condition	Medication
AL	CARES	X	X	X	X	X	X	X	X	X	X	X	X
CA	CDER	X	X		X	X	X	X	X	X	X	X	X
CO	CCMS	X	X	X	X	X	X	X		X	X	X	
	COPAR	X	X	X	X			X		X	X	X	X
CT	CAMRIS	X	X	X	X	X	X	X	X	X	X	X	X
DE	PACT	X	X	X	X	X	X	X	X	X	X	X	X
FL	ABC Control System	X	X	X	X	X	X	X	X	X	X	X	
HI	DD Information System	X	X	X	X					X	X	X	X
ID	IOC-Medicaid	X	X		X	X	X	X	X	X	X	X	X
KS	DDP	X	X		X	X	X	X	X	X	X	X	
	KRIS	X	X	X									
MI	CMHDSS	X	X	X	X	X	X	X	X				
MN	Client Tracking/Management Support Info. Systems	X	X	X	X	X	X	X		X	X	X	X
MT	MIIS	X	X	X	X	X	X	X		X	X	X	X
NM	COOP	X	X	X	X	X	X	X		X	X		X
NY	TABS	X	X	X	X	X	X	X		X	X	X	X
OH	OPD	X	X	X	X	X	X	X	X	X	X	X	X
OK	DD Q. A. Questionnaire	X	X	X	X	X	X	X		X	X	X	X
OR	CPMS	X	X	X	X		X	X		X	X	X	X
PA	FACT	X	X	X	X	X	X	X	X	X	X	X	
	CRF	X	X	X	X					X	X	X	
SD	ICAP	X	X	X	X	X	X	X		X	X	X	
	Service Record	X										X	X
TX	Level of Care (LOC)-3650	X	X		X	X	X	X	X	X	X	X	
	CARE-MHMR				X					X	X		
UT	USSDS-DSPD	X	X	X	X	X	X	X	X	X	X		
	ICAP	X	X	X	X	X	X	X		X	X	X	X
VT	QSR	X	X	X	X								
WA	DDD-MIS	X	X	X	X	X	X	X		X	X		
WY	ICAP	X	X	X	X	X	X	X		X	X	X	X

TABLE 2: Functional Characteristics

State	Data Base	Self-Preservation	Toileting	Dressing	Mobility	Eating	Communication	Problem Behavior	Dual Diagnosis
AL	CARES				X	X	X	X	X
CA	CDER	X	X	X	X	X	X	X	X
CO	CCMS				X		X	X	X
	COPAR	X	X	X	X	X	X	X	X
CT	CAMRIS				X	X	X	X	X
DE	PACT	X	X	X	X	X	X	X	X
FL	ABC Control System	X			X			X	X
HI	DD Information System	X	X	X	X	X	X	X	X
ID	IOC-Medicaid	X	X	X	X	X	X	X	X
KS	DDP	X	X	X	X	X	X	X	X
	KRIS								
MI	CMHDSS								X
MN	Client Tracking/Management Support Info. Systems	X	X	X	X	X	X	X	X
MT	MIIS	X	X	X	X	X	X	X	X
NM	COOP							X	X
NY	TABS	X	X	X	X	X	X	X	X
OH	OPD				X		X	X	
OK	DD Q. A. Questionnaire	X	X	X	X	X	X	X	X
OR	CPMS								
PA	FACT				X		X	X	
	CRF							X	X
SD	ICAP	X	X	X	X	X	X	X	X
	Service Record								
TX	Level of Care (LOC)-3650		X	X	X	X	X	X	X
	CARE-MHMR						X	X	
UT	USSDS-DSPD								
	ICAP	X	X	X	X	X	X	X	X
VT	QSR								
WA	DDD-MIS								
WY	ICAP	X	X	X	X	X	X	X	X

TABLE 3: Residential Service Types and Funding Sources

State	Data Base	Nursing Home	State Inst.	Non-State Inst.	State Group Home	Non-State Group Home	Foster Home	Semi-Ind. Living	Supp. Living	Family/ Relative Home	Other Res.	Waiting for Services	Funding Source: ICF-MR	HCBS	CSLA	State-only
AL	CARES	X	X			X	X	X	X	X	X	X	X			
CA	CDER	X	X	X	X	X	X		X	X	X		X	X	X	
CO	CCMS	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	COPAR	X	X	X	X	X	X		X	X	X	X	X	X	X	X
CT	CAMRIS	X	X	X	X	X	X	X	X	X	X	X	X	X		X
DE	PACT		X		X		X	X	X	X		X				
FL	ABC Control System	X	X	X	X	X	X		X	X	X	X	X	X	X	X
HI	DD Information System	X	X	X	X	X	X	X	X	X	X					
ID	IOC-Medicaid		X			X							X			
KS	DDP	X	X	X						X	X	X	X	X		
	KRIS		X	X				X	X		X	X				
MI	CMHDSS	X	X	X	X	X	X	X	X	X	X		X	X	X	X
MN	Client Tracking/Management Support Info. Systems	X	X	X	X	X	X			X		X	X	X		
MT	MIIS	X	X			X	X	X	X	X		X	X	X		X
NM	COOP	X	X	X		X			X	X	X	X	X	X		X
NY	TABS	X	X	X	X	X	X	X	X	X	X	X	X	X		X
OH	OPD	X	X	X	X	X	X	X	X	X	X	X	X	X		X
OK	DD Q.A. Questionnaire	X	X	X	X	X	X	X	X	X	X		X	X		X
OR	CPMS	X	X	X	X	X	X	X	X	X	X	X	X			
PA	FACT		X										X			X
	CRF			X	X	X	X	X	X	X			X	X		
SD	ICAP	X	X			X	X	X	X	X						
	Service Record					X	X	X	X	X		X	X	X		X
TX	Level of Care (LOC)-3650		X	X	X	X	X	X	X	X			X	X		
	CARE-MHMR		X	X	X	X	X	X	X	X	X		X	X		X
UT	USSDS-DSPD			X	X	X	X	X	X	X		X				X
	ICAP	X	X	X	X	X	X	X	X	X		X	X			
VT	QSR	X	X			X	X	X	X	X	X		X	X		X
WA	DDD-MIS	X	X	X	X		X	X	X	X	X	X	X			X
WY	ICAP	X	X			X	X	X	X	X		X	X			

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